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The Suitability of Patient Education Materials for Poor and Underserved Populations in a Large Metropolitan Area

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Keywords: health literacy, health education, patient education materials

Abstract: This study analyzed patient education materials provided to poor and underserved patients treated by safety-net providers. A content analysis was conducted to evaluate the materials' formatting and written style, readability, pictorial content, source, and cultural appropriateness.

Background

Safety-net providers provide health services and prescription drugs at low cost to poor and underserved patients. There are many reasons why a patient may need to consult a safety net provider, but poverty, lack of health insurance and prescription drug coverage are major causes. Approximately 43.6 million Americans have no health insurance, and many more do not have viable access to adequate healthcare (Geller, Taylor, & Scott, 2004). Safety-net providers often serve the most vulnerable patients including inner-city, low-literate, and socio-economically disadvantaged people from minority cultural groups (Lasch et al., 2000; Tobler, 2000).

Patients are increasingly being asked to take more responsibility for self-care in a complex health care system and this can be a challenging prospect for even the most educated. Patient education materials are an important method of health communications about medical treatment and health behaviors, but their value depends on how useful patients perceive them to be. Patients' use of written health information is greatly influenced by its readability and cultural sensitivity. The link between poverty, low health literacy and poor health outcomes has been well established (Andrus & Roth, 2002; Berkman et al., 2004; Schillinger et al., 2003). Health literacy, defined as the ability to read, understand, and act on health care information, includes the ability to comprehend prescription labels, insurance forms, and other health-related information (Kirsch et al., 1993). The 1992 National Adult Literacy survey revealed that as many as 90 million adults in the United States may be deficient in the functional reading and math skills needed to effectively navigate the health care system (Kirsch et al., 1993). Studies have documented the difficulties that many patients have with written health materials and the negative consequences for their health (Davis et al., 2002; Schillinger et al., 2003).

Health information can play an important role in fostering patients' self-care behaviors (Wilson, Baker & Brown-Syed, 2000), yet numerous health-related materials are written well above the average reading ability of many adults (Estey, Musseau & Keehn, 1991). For example, an examination of 51 patient education brochures published by the American Cancer Society found that the reading level ranged from a grade level of 5.8 to 15.6, with an average of 11.9 (Meade, Diekmann & Thornhill, 1992). Given that the reading level of the average American adult is 8th grade, and many read below a 5th grade level, safety-net providers are likely to see a significant proportion of patients who struggle with health information and have difficulty navigating the healthcare system (Kirsch et al., 1993). Low health literacy may be found in all

social classes, however, those people with chronic diseases, limited education, and living in poverty are disproportionately affected (Schillinger et al., 2003).

Cultural appropriateness is another important aspect of effective health communications (Lasch et al., 2000). The U.S. patient population is increasingly diverse, which affects not only traditions of language, dress and diet, but also patients' perceptions of illness, health beliefs and practices (Núñez, 2004). The poor and culturally diverse patient bears a disproportionate share of poor health conditions and outcomes (NMA Cultural Competence Primer). The convergence of the growing diversity of cultures within the U.S. and the increasing complexity of the healthcare system provides significant challenges for patient education. Lack of cultural understanding among health providers contributes to health disparities, and the projection of stereotypes can impede clinical decision-making (Geiger, 2000). Language, ways of communicating, health beliefs and practices can all constitute a source of misunderstanding. Some evidence suggests that the representation of cultural groups in patient education materials has an impact on patients' retention and use of health information (Weintraub et al., 2004). For example, culturally and linguistically appropriate interventions were found to enhance the rate of cervical screenings obtained by Chinese immigrant women residing in North America (Taylor et al., 2002). More favorable responses to culturally relevant patient education materials can be expected although research has not always confirmed this.

This study sought to explore patient education and preventive health care services for patients seen at Richmond, Virginia area safety-net providers. Specific objectives included: collecting patient education materials available to patients, determining the literacy level required to read the materials collected, and conducting a content analysis that examined the materials' linguistic and visual message, potential for bias, cultural and age representations, and appropriateness and accessibility for the patient populations using the safety-net providers. The cultural appropriateness of patient education materials for the populations served by Richmond area safety-net providers was analyzed and recommendations for the selection and creation of suitable health education materials developed.

Methodology

Content analysis is a research tool that facilitates making valid inferences from written text or artifacts of social communication (Berg, 2004; Weber, 1990). For this study, patient education brochures distributed to patients by 10 safety-net providers in the Richmond, Virginia area were collected and analyzed regarding the brochures' formatting and written style, pictorial and linguistic content, readability, the race or age of people portrayed, potential for bias, and appropriateness for the demographics of the patients. They consisted of brochures, pamphlets, or photocopied handouts that describe a disease state, medication, or preventive health message. Three hundred and ninety-three unique items were collected and analyzed. Readability was estimated using the Gunning-Fog Index, a manual calculation in which the length of the average sentence length and number of polysyllabic words in a 100-word sample of text are used to calculate an estimate of the reading level required to read them (Roberts, Fletcher, & Fletcher, 1994). To verify the results of the content analysis, a second researcher reviewed a 5% sample of the materials using the same recording form. Inter-rater reliability was 92.5%. The estimations of readability were verified with the Flesch Reading Ease score and Flesch-Kincaid grade level score, reading statistics incorporated into Microsoft Word.

Findings

Generalizations were made based on the results of the analysis, compiled into data specific to each safety-net provider and then into a matrix of results that combined data from all the safety-net providers. To maintain patient confidentiality, the clinics will not be identified by name and only aggregate data is reported. Aggregate demographic information about patients using the safety-net providers was supplied by a coordinating agency for safety-net providers in the Richmond area, and was used to complete some parts of the content analysis. The results are reported in the following categories: content, graphics, typography and format, literacy demand, and cultural appropriateness.

Almost 10% of the patient education materials described an acute disease state, while 59% described chronic disease states. Some disease states (9%) could be considered either acute or chronic such as sexually transmitted diseases like herpes. The remainder promoted healthy lifestyles or preventive healthcare including health screenings. Seventy percent of the documents contained information that was less than 10 years old, and the information was considered to be medically accurate. No instance was recorded of overt medical misinformation. However, 17% of the documents distributed by safety-net providers were more than 10 years old. In some cases, no information was provided regarding the publication date. Thirteen percent could not be evaluated because they were written in Spanish and other languages. Most of the materials contained technical words or jargon; however many times these were explained immediately in the text or in a glossary. Only 6% of the materials contained unexplained acronyms or medical jargon. Seventy percent were written in an active voice, while 30% were written in passive voice.

Thirty-nine percent of the materials were produced by a pharmaceutical or medical device production company, 26% by a public health agency, and 19% by disease-related organizations such as the American Diabetes Association. Other sources included a health professions organization (2.8%), a medical center (1.3%), and publishing agencies (4%). Some materials did not identify a source, and some had more than one such as when a pharmaceutical company partners with or provides a grant to another agency. In most cases (72%), the patient education materials were non-biased meaning that 1) they did not promote a particular drug or service, or 2) if a particular drug was mentioned the major health risks and a reference to obtain further information were presented as is required by FDA law. If a drug was promoted, it was usually mentioned at the end after disclosing pertinent health risks of the disease state. However, 15% of the materials appeared to have some bias.

Of all the patient education materials collected, 67.7% contained pictorial images. Of these, 48% of the visual images used were clear, while the remainder were considered to be confusing. The ones that were assessed as having clear images contained pictures of familiar objects and symbols, whole body images instead of isolated body parts, and visual images that were accompanied by some sort of caption or label. Fifty-nine percent of the illustrations were appropriate for their intended audience, meaning that they were consistent with the demographics of the patient population using the safety-net providers and portrayed realistic scenarios. Thirty-two percent did not contain photographs or illustrations

Forty-nine percent of the materials were printed on glossy paper, 42% on non-reflective or plain paper, and 9% were photocopied. Approximately 78% of the patient education materials emphasized important concepts through the use of bold type, italics, bullets or numbers to lead the reader's eye to the main points of the presented information. Most of the materials used a font size in which the style and size of the font was appropriate but 22% contained type that was

too small or hard to read. A sufficient amount of contrast between the words and background to facilitate reading was present in 85% of the materials.

Based on the Gunning-Fog Index, only 42% of the materials contained information that was estimated to be at a 5th grade reading level or below meaning they could be adequately read and understood by someone with the equivalent of a 5th grade education. Grade levels were not rounded up, meaning that a score of 9.9 would be determined to have a Grade 9 reading demand. The results were verified by using OCR software to scan a 5% sample of the patient education materials into Microsoft Word and using the Flesch Reading Ease score and the Flesch-Kincaid Grade Level estimate. A 5% sample was chosen because of the volume of patient education materials collected in this study. Twenty brochures were analyzed in this way, and it appears that the Gunning-Fog Index tended to underestimate reading difficulty compared to the Flesch-Kincaid Grade Level Score.

African-Americans were the only race portrayed 3% of the time, Latino/as-Americans 1.3% of the time, and Caucasian-Americans 36% of the time. Asian-Americans were never portrayed by themselves in the sample collected. The materials were analyzed to determine if diverse groups of patients were portrayed in patient education materials. Approximately 47% of the materials contained pictures of two or more ethnic groups, and 13% did not. Forty percent did not contain illustrations of people. Similarly, 48% of the materials contained images of two or more age groups. Forty-seven percent of the materials excluded certain age or ethnic groups, while 18% did not. There were instances in which a group was excluded because it was appropriate to the topic, e.g., no children were portrayed on a brochure about urinary tract infections in the elderly. Approximately 60% of the materials were appropriate for their intended audience, meaning that they portrayed realistic scenarios and the portrayals of people were inclusive of the patient demographics of people served by the safety-net providers.

Patient Education Activities

Interviews with clinical staff members of the 10 safety net providers were conducted in person or by telephone, depending on their preferences and schedule. In either case, the researcher visited each health center to gather patient education materials and to ascertain patient access to materials. The interview questions were based on five topics: 1) structure of the clinics, 2) pharmacy activities, 3) types of patient education available to patients, 4) reading level of the clientele, and 5) primary languages of the clientele. Only 20% of the clinics have a licensed pharmacy located in their building, albeit a small one. However, all of the clinics provide some sort of medication assistance through pharmaceutical manufacturer patient assistance programs, medication samples and partnerships with local retail pharmacies. Unfortunately, because of the different ways safety-net provider are able to provide prescription medicines, many do not have the advantage of providing one-on-one patient counseling by a pharmacist.

All of the clinics provide both verbal counseling and patient education materials consisting primarily of published brochures. Approximately 40% of the health centers displayed patient education materials in the waiting area, 20% of the health centers made patient education materials available inside the exam area, and 40% located materials both inside the exam area and in the waiting area. In 40% of the clinics, it was up to the patient to pick up patient education materials. It was the health professional's responsibility to give materials to the patient in another 30% of the clinics, and in the remaining 30% of the clinics, the practitioner may make the materials available or patients may access the materials themselves. In addition, approximately 70% of the clinics provide patient education materials regarding health education and preventive

care. More than half (60%) referred patients to health education classes or support groups provided by other agencies.

Approximately 30% of the clinical staff members estimated that many of their patients read at a 6th grade level, 20% at a 7th grade level, 40% at a 9th grade level, and 10% at a level higher than 9th grade. In 60% of clinics, the number of patients who cannot speak English very well or at all was estimated to be 10% or less. Twenty percent of clinics estimated that the number of their clientele who cannot speak English very well or at all to be 21-30%, 10% to be 31-40%, and 10% to be at or above 50%. Of those patients whose primary language is not English, 30% of the clinics have patients who speak African languages and Russian, 10% Afghani, Asian, other Eastern Europe languages, Indian languages, and Portuguese, 20% Farsi and French, and 100% of the clinics serve patients who speak Spanish as their primary language. However, only 70% of the clinics are able to provide Spanish speaking interpreters.

Conclusions/Implications

The results of this study bear out much of what has been written about patient education materials. In selecting patient education materials, community-based health centers should attempt to be vigilant about several issues. Most importantly, there appears to be a mismatch between the reading levels of the patient population using the safety-net providers and the patient education materials available to them. Given the apparent tendency of the Gunning-Fog index to underestimate reading demand, the number of materials written at a level most adults could read might be even lower than estimated. Reviewing patient education information for currency and accuracy would ensure that the materials are meeting up-to-date medical guidelines. Materials could also be reviewed for the use of unexplained medical jargon which is especially problematic for a low literate population. Similarly, unclear or confusing illustrations should be a red flag. Text that is written in a font size and style that is difficult to read is also an issue to consider since both limit the usefulness of materials. Other issues that can contribute to difficulty with reading include the use of glossy paper, lack of contrast, and use of the passive voice, and this was present in a substantial number of the patient education materials.

A significant proportion of available patient education materials did not represent the demographics of the client population using the safety-net providers. While representative materials may not be easily available, every effort should be made to obtain them. Given the variety of primary languages spoken by the patient population, the clinics may wish to take advantage of translated patient education materials that are available online in a variety of languages. Patient education materials that promote drug products should be scrutinized for bias. Some patients may not have the sophistication to understand the information presented about medication risks or pursue references to other sources of information; therefore guidance from health practitioners is essential. It must be recognized that the safety-net providers' number one priority is provision of medical care for their underserved populations, and auxiliary services such as patient education often fall by the wayside due to minimal staffing and budget constraints. However, patients with limited reading abilities and unfamiliarity with western cultures can be confused, misled, or deceived by patient education materials that are not well chosen. Health education is a vital component of medical communications and failure is not an option especially in regards to the most vulnerable populations in society, namely the poor and uninsured.

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